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Background: Chronic heart failure (HF) may cause great suffering for both patients and their families. Family members have an important role in supporting the patients managing the self-care. Patients and their families need support in order to be prepared to deal with the HF symptoms and its effects on daily life and well-being and the self-care regimen. However, their needs must be further explored. Aim: To describe the self-assessed needs of supportive care in patient-partner dyads affected by HF.

Methods: The study has a family perspective defining the patient-partner dyad as the family. Dyadic processes are based on the assumption that each participant affects and is affected by the other. Focus group interviews were performed with patient-partner dyads affected by HF. The interviews were led by a moderator using an interview guide and with an observer supporting the data collection including documentation of memos and non-verbal activities. The interviews were tape-recorded, transcribed verbatim and analyzed using content analysis.

Results: The preliminary analysis is based on 8 focus group interviews including 19 patient-partner dyads (mean age patients 72 years, partners 70 years, 63 % male patients). During the initial analysis seven themes were identified that described the self-assessed needs of supportive care: (1) Continuous regular follow-up visits at a heart failure clinic, (2) Easy access to care through telephone hours, (3) Support from health care professionals, (4) Consolation from other dyads and from health care professionals, (5) Planned joint visits, (6) Education given in patient-partner groups, (7) Learning from others. The patient-partners dyads described their needs for easy access to care and long-term support from HF specialists. To increase knowledge about the heart disease and its self-management and to have a lifeline through someone to turn to for advice and consolation were emphasized. They also suggested that the supportive care should be given to both the patient and the partner and also in groups with other patient-partner dyads in the same situation.

Conclusion: The results highlight the importance of including partners in the care. The result can guide the design of new intervention to fulfill the needs of education and support for dyads affected by HF.

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The contribution of caregivers to self-care in heart failure: development of an instrument

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Purpose: The purpose of this study was to develop an instrument for measuring the contribution of caregivers to self-care

in adults with heart failure (HF). Contribution of caregivers to self-care was defined as the provision of care in the behalf of another person who needs to perform HF self-care; in some cases caregivers only make recommendations to patients, but when patients are unable to perform self-care, caregivers may substitute for patients. This instrument, referred to as the Caregiver Contribution to Self-Care of Heart Failure Index (CC-SCHFI), was developed modifying the Self-Care of Heart Failure Index version 6.2 (Riegel et al., 2009).

Methods: A descriptive design was used to study 291 caregivers of adults with HF recruited from 16 cardiovascular centers located across Italy.

Data collected included an investigator-designed survey of socio-demographic and clinical characteristics and the CC-SCHFI. The CC-SCHFI is composed of three scales: the self-care maintenance scale (10 items) that measures the caregiver's contribution to symptom monitoring and adherence behaviors; the self-care management scale (six items) that evaluates symptom recognition, treatment implementation and treatment evaluation by caregivers; and the self-care confidence scale that measures caregiver's confidence in his/her contribution to the patient's self-care.

Results: Caregivers were mainly female (65.7%) with a mean age of 59.2 years (SD 14.6). In 89% of cases caregivers were the spouses or the children of the patients. Test-retest reliability showed excellent Intraclass Correlation Coefficient (0.92 for self-care maintenance, 0.94 for self-care management and 0.93 for self-care confidence). Comparing the CC-SCHFI scores of caregivers who had received HF education versus caregivers who had not, significant and clinically meaningful differences were found (p < 0.001). In Confirmatory Factor Analysis, the factor structure of the CC-SCHFI revealed good model fit: Self-care maintenance, Chi-square 33.47, p 0.11, CFI = .980, NNFI.963; Self-care management, Chi-square 11.74, p 0.16, CFI = .971, NNFI.945; Self-care confidence, Chi-square 5.86, p 0.31, CFI = .999, NNFI.99.

Conclusions: The CC-SCHFI has good psychometric properties and can be used to measure the extent to which caregivers contribute to HF self-care. Researchers using the CC-SCHFI will be able to identify where caregivers contribute to patients' self-care efforts, thereby identifying where caregivers need additional support.

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Validity and reliability of the German version of the 9-item European Heart Failure Self-care Behaviour Scale

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